DOCUMENT RESUME

ED 421 807 EC 306 562

| | |
|---|---|
| AUTHOR | Levine, Karen |
| TITLE | Williams Syndrome Information for Teachers. |
| INSTITUTION | Williams Syndrome Association, Clawson, MI. |
| PUB DATE | 1997-00-00 |
| NOTE | 12p. |
| AVAILABLE FROM | World Wide Web: http://www.williams-syndrome@org/teacher.htm |
| PUB TYPE | Guides - Non-Classroom (055) -- Reports - Descriptive (141) |
| EDRS PRICE | MF01/PC01 Plus Postage. |
| DESCRIPTORS | Congenital Impairments; Elementary Secondary Education; Inclusive Schools; *Learning Problems; *Neurological Impairments; *Personality Traits; *Special Health Problems; *Student Characteristics; Symptoms (Individual Disorders); Teaching Methods |
| IDENTIFIERS | *Williams Syndrome |

ABSTRACT

This paper uses a question-and-answer format to summarize information about Williams syndrome, a neurobehavioral congenital disorder which affects development in cognitive, behavioral, and motor areas. Questions address the following topics: characteristics of Williams syndrome; medical problems associated with Williams syndrome; characteristic facial features of children with Williams syndrome; characteristic personality and behavior patterns of these children (specific teaching strategies for each characteristic are suggested); characteristic learning patterns; the use of regular IQ testing with children having Williams syndrome; nine common areas of learning strength (such as expressive vocabulary, long term memory for information, and musical ability); four common areas of learning difficulty and teaching strategies (such as tasks requiring fine motor or visual-motor integration skills); the inclusion of children with Williams syndrome in regular classes; special therapies; explaining Williams syndrome to other children; and sources of more information. (DB)

**********
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
**********

ED 421 807

# WILLIAMS SYNDROME
# INFORMATION FOR TEACHERS

BY

KAREN LEVINE, PH.D.
PSYCHOLOGIST, CO-DIRECTOR
WILLIAMS SYNDROME PROGRAM
THE CHILDREN'S HOSPITAL
BOSTON, MA

PERMISSION TO REPRODUCE AND DISSEMINATE THIS MATERIAL HAS BEEN GRANTED BY

BT. FAY

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

1

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

This document has been reproduced as received from the person or organization originating it.

Minor changes have been made to improve reproduction quality.

Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

## *Introduction*

This pamphlet was developed to assist teachers who have a child with Williams syndrome in their class at school. The most important sources of information about any child are, of course, the child himself, and the child's family. Parents, brothers and sisters, and environmental factors strongly influence the development and personality of all children. Other genetic influences also affect the child. For a child with Williams syndrome, the syndrome is only one factor in who he or she 'is'.

Children with Williams syndrome are predisposed to certain difficulties, with a great deal of variety across each of the characteristics associated with the syndrome. For example, some of the children have few or no associated medical problems. The degree of learning difficulty also varies greatly, as does the presence and degree of attention difficulty. The patterns of behavior and learning discussed in this pamphlet reflect potential areas of difficulty, rather than characteristics of all children with Williams syndrome. The particular child in your class may have few or all of the tendencies discussed below.

Familiarity with common trends or propensities and beneficial strategies can be very helpful, especially in terms of understanding and working with children who have confusing behaviors and learning patterns. We will provide background, educational and related information about Williams syndrome and then delineate specific strategies for Williams syndrome related problems.

## *What is Williams syndrome?*

Williams syndrome is a neurobehavioral congenital disorder that occurs sporadically. That is, it does not run in families. It is not due to any medical, environmental or psychosocial factors, but rather occurs as a "fluke." It is quite rare, occurring in about 1 of every 20,000 births. Williams syndrome impacts several areas of development including cognitive, behavioral and motor areas.

Most infants with Williams syndrome are colicky for the first several months of life, with great difficulty sleeping. Eventually (usually during the first year, and often rather suddenly) the fussiness disappears and the children begin to sleep much better. They generally become delightful, happy babies, much to the relief of their sleep deprived parents! The source of this early fussiness is not yet known, but may be due to some sort of stomach pain. This is naturally a very stressful time for the family.

EC 306 562

In regard to motor development, children with Williams syndrome usually begin walking later than would be expected. This is often due to a combination of coordination, balance and strength issues. The children also tend to have fine motor difficulties apparent from an early age, also due to strength and coordination difficulties.

Cognitively, there is a great deal of variety among the individuals. Some children display average or above average ranges of intelligence with a learning disability. Many children are in the borderline or mildly retarded range, and some are in the moderate range of mental retardation. Most significantly, most children show quite significant scatter in the level of their abilities across domains.

Children with Williams syndrome are usually quite social and nonverbally communicative from infancy. They will use facial expression, eye contact, and eventually gestures to communicate. They begin talking later than is normally expected. There is a great deal of variety in the course of early language development, but usually, by 18 months of age, children with Williams syndrome begin talking by using single words, and often phrases as well. They may show a strength in learning songs, revealing a good auditory memory as well as musical sense. Many children with Williams syndrome begin talking in sentences at approximately 3 years, and by 4 or 5 years, language becomes, and continues to be, a source of relative strength.

### *Are there medical problems associated with Williams syndrome?*

Children with Williams syndrome tend to be healthy, but need to be monitored medically in certain areas. Heart, kidney and dental problems are quite common. Generally, these problems can be treated if dealt with as they occur.

Children with Williams syndrome often need to urinate more frequently than most children. The reason for this occurrence is not yet known. Unobtrusively allowing children to go to the bathroom at unscheduled times may be necessary.

Children with Williams syndrome are often shorter than would be expected when compared to the heights of their parents, but they are generally within the normal range for children of their age.

If there is a child in your class with Williams syndrome it is important that they see a pediatrician and are monitored by a cardiologist. The children often have some coordination, balance, back and joint problems and should be seen by a physical therapist.

### *Do children with Williams syndrome look alike?*

Children with Williams syndrome generally have characteristic facial features including a small upturned nose, curly hair, full lips, full cheeks, small teeth, a broad magnetic smile and often especially bright eyes. While the resemblance among children with Williams syndrome can be strong, they, like all children, look like their parents!

### *What characteristic personality and behavior patterns are associated with Williams syndrome?*

Certain personality characteristics are especially common in children with Williams syndrome. These characteristics include: an outgoing social nature, an exuberant enthusiasm, a sense of the dramatic, overfriendliness, a short attention span, extra sensitivity to sounds (hyperacusis), and anxiety - especially about upcoming events.

Children with Williams syndrome are often particularly appealing. Many of the associated characteristics are rather desirable (bright eyes, very broad engaging smile, enthusiastic manner, socially engaging and conversational, strong sensitivity to the emotions of others, cute upturned nose, excellent memory for people met infrequently or long ago, very expressive of own emotions - especially happy

excitement). It is important to keep in mind that these are indeed "real" characteristics of the child, and not just 'syndromal'. That is, it is important to capitalize on, and enjoy the very real charismatic appeal of many children with Williams syndrome, and not dismiss these behaviors as simply, "Williams-isms."

Some behavioral characteristics associated with Williams syndrome can pose challenges in classrooms. There are effective strategies for minimizing the difficulties and helping the child cope. These characteristics and strategies are outlined below.

### 1a. Characteristic:

*Short attention span and distractibility

Attention difficulties often lead to associated difficulties such as impulsivity which can result in the child not following directions well, getting out of their seat, etc.

### 1b. Strategies:

In general, the same approaches that are helpful for all children with attention problems are also effective for children with Williams syndrome.

*flexibility in requirements for time spent working

*frequent 'breaks' in work time

*a "high success," high motivation curriculum

*minimal distractions; auditory as well as visual

*rewards for attending behaviors and, when possible, redirection around 'off task' behaviors or ignoring same

*allowing some degree of choice for the child in terms of activity

*small groups

*consultation with a behaviorist familiar with positive behavior management approaches

### 2a. Characteristic:

*difficulty modulating emotions

Examples:

*extreme excitement when happy

*tearfulness in response to apparently mild distress

*terror in response to apparently mildly frightening events

### 2b. Strategies:

*Decide when this is a problem. For example, expressing enthusiastic excitement, albeit impulsively or without raising a hand, may be beneficial to the motivation of the class as a whole, whereas frequent tears and a high degree of anxiety is problematic for the child with Williams syndrome as well as the other children.

*Help the child to develop increasingly effective internal controls to modulate emotions while adapting the environment to minimize situations of extreme anxiety and frustration.

**Examples:**

*Anticipate beginning buildup of frustration. Help the child to remove himself from the frustrating situation and find a different activity before the frustration escalates

*Minimize unexpected changes in schedule, plans, etc.

*Use stories and role play/pretend play to act out various anxiety provoking situations with the child

**3a. Characteristic:**

*Heightened sensitivity to sounds (hyperacusis)

This characteristic in combination with a tendency toward anxiety sometimes causes behavior problems around noise related activities such as fire drills, vacuum cleaners, ceiling fans, heating or plumbing systems, and school bells.

Some children may become distracted, overly excited or fearful at these events.

**3b. Strategies:**

*provide warning just before predictable noises when possible (fire drills, hourly bells etc.)

*allow the child to view and possibly initiate the source of bothersome noises (e.g. turn the fan on and off, see where the fire alarm is turned on)

*make tape recordings of the sounds and encourage the child to experiment with the recording (playing it louder/softer etc.)

**4a. Characteristic:**

*Perseverating on certain "favorite" conversational topics

Some children with Williams syndrome have "favorite" topics that they want to talk about more often than is socially appropriate. Sometimes these favorite topics have to do with things that make them anxious such as fire trucks, trains or lawnmowers. Other children may show overwhelming fascination with, or interest in bones or other topics related to the body. Some fascination with things that are scary is quite normal in people generally (hence our interest in horror movies or 'thrillers') although this tendency can be particularly acute in children with Williams syndrome. Sometimes favorite topics are simply areas the child is confident discussing, and the child may be relying on that topic to ensure that he/she will be a competent participant in the conversation.

**4b. Strategies:**

*include social skills teaching as part of the IEP. Use role play, stories, discussion and small group experiences to teach alternative appropriate topics, and expand the child's repertoire

*When the favorite topic involves repetitious asking of the same question (e.g. which day are we having a fire drill) first respond sufficiently to make sure the child has understood the requested information. (you can check this by asking the child the same question) Then ignore the subsequent repetitions, while offering other topics and activities. Avoid a discussion of whether or not the topic will continue to be discussed as this prolongs the perseveration

*Provide some time for discussion of the child's favorite topic

*Capitalize on the favorite interest as a curriculum topic. The child will approach curriculum based on favorite topics with a high level of motivation

**5a. Characteristic:**

*Anxiety around unexpected changes in routine/schedule

**5b. Strategies:**

*Provide a predictable schedule and routine with specific warnings (e.g. a specific song a few minutes before cleanup time) marking daily transitions

*Minimize unexpected changes

*For preschool aged children: use of picture schedules for daily routines, and wall calendars with big squares on which special events can be sketched are helpful.

*For older children: use digital watches and date books

*Evaluation of other issues which might be making a child susceptible to feeling anxiety or a loss of control around changes

*Capitalize on the child's orientation to a predictable schedule to work in less desirable but necessary activities at predictable times

**6a. Characteristic:**

*Rocking, nail biting or skin picking

Usually these behaviors are fairly mild and may not pose a problem. It is important to realize that many of these behaviors may simply be outside the child's capacity to consistently control. Therefore, you should not dwell on them or continually remind the child not to do the behavior. 6b. Strategies:

*Ignoring the behaviors when possible while trying to lower environmental stress is usually sufficient to reduce them

*If the behavior bothers the child or other children, sometimes occasional reminders in conjunction with behavioral techniques can be helpful (e.g. a sticker for each hour without nail biting)

**7a. Characteristic:**

*Difficulty building friendships.

In spite of a tendency to have a very sociable nature, children with Williams syndrome often have difficulty building friendships. This is probably due to difficulties around sustaining attention, and impulsivity, as well as developmental and learning difficulties. Many of the children are, however, able to develop true friendships and this should be a goal included as part of the children's educational development. This may require extensive initial help from teachers.

**7b. Strategies:**

*Include social skills development as a "Goal" in the child's IEP

*Work as a team with the child's parents regarding promoting a friendship with another likely friend.

Encourage mutual visiting at homes

*Facilitate social interaction during teaching activities (e.g. have the child with Williams syndrome and a likely friend pair up in working on a project or reading a story together)

*Consider a variety of relationships for friendship building, including older or younger children and children with or without special needs

### *Are there characteristic learning patterns in children with Williams syndrome?*

Most children with Williams syndrome have some learning difficulties. However, there is a wide range in the degree of these difficulties. Some of the children function in the "Above Average" or "Average" range, many in the "Borderline" range, and others in the "Mild" range of mental retardation. Some of the children show moderate mental retardation, and a few function in the severe range of mental retardation. Children with Williams syndrome tend to show substantial scatter in the level of their abilities across domains, and the range of scatter is greater than in most children. The children tend to have relatively predictable areas of strength and weakness, although there are exceptions. For example, it would not be uncommon for a 6 year old child with Williams syndrome to have a vocabulary and general fund of information at close to age level, with reading and math skills at a 3 year level. Therefore, establishing IQ level and determining optimal classroom placement are often challenging processes.

### *Can regular IQ testing be done on children with Williams syndrome?*

Regular IQ testing can be very helpful to get information about areas of learning strength and weakness in children with Williams syndrome. However, correct interpretation is very important. If the child shows significant scatter in the level of his/her performance across domains, it does not make sense to "average" these very different levels to obtain n IQ score. For example, it would not make sense to average an 8 year old child's age appropriate vocabulary with his 3 year level of design copying skills and conclude he is at a 5 year level and mildly retarded! Rather it is more meaningful to discuss the child's level of performance in specific areas and to plan curriculum according to these different levels. For example, the child may be ready to understand 3rd grade science curriculum but may need first grade math instruction.

### Tips for IQ testing:

The examiner should be especially aware of word finding difficulties, which can cause test scores on verbal response material to be lower than actual functioning level. A "testing the limits" approach (e.g. providing some auditory or gestural cueing) is especially helpful and scores can be reported both with and without cueing. Subtests involving visual motor integration or spatial analysis (e.g. "Coding," "Block design," "Mazes," the "VMI") will usually be very low which is important information **but distinct from "intelligence."** A test such as the Kaufman Assessment Battery for Children (most useful for children 4 - 12 years) has subtests which assess particular areas **of strength such as visually based non spatial learning. Testing in several sessions may be necessary to work around attention difficulties.**

### *What are common areas of learning strength for children with Williams syndrome?*

The following list of strengths indicates areas of strength relative to the child's own abilities, not necessarily relative to the abilities of their peers.

### *Expressive vocabulary

The excellent vocabulary of many children with Williams syndrome is a characteristic that is usually quite apparent to others. This area is often the highest for a child in terms of "test-age". It is common for

children with Williams syndrome to use somewhat unusual words and phrases. This is probably due to a combination of excellent auditory memory skills and some difficulty with language processing, resulting in language being encoded in 'chunks'. It is important not to expect all areas of a child's functioning to be at the level of their vocabulary.

***Long term memory for information**

Once children with Williams syndrome have learned information they tend to be relatively good at retaining it. This applies to academic material as well as events, names etc. While it may be more difficult to initially teach new material, it is worth the effort since what is learned is generally retained. The exception to this is spatially loaded material such as letters, left and right (while children are still learning them), and finding their way around, which can remain difficult concepts for some time.

***Hyperacusis/Sensitive Hearing** The sensitive hearing found in many children with Williams syndrome can be capitalized on to develop reading skills. Phonetic approaches to reading are often very successful since the child is able to readily hear letter sounds (especially beginning and ending) and use them to develop word finding skills.

***Ability to get information from pictures such as photos, illustrations, and videos**

These mediums should be used extensively as teaching aids to accompany verbal teaching. Children with Williams syndrome are often particularly motivated to work with picture oriented material. "Whole language" approaches to reading can often be used to augment the more traditional phonics approach.

***Ability to learn through actual "hands-on" experience**

A hands-on component to learning experiences can often help children with Williams syndrome sustain attention.

***Musical ability**

Extraordinary musical ability seems more common in children with Williams syndrome than in other children. A love of, and some sense of, music is quite common in these children. Utilizing songs and musical instruments can be ideal for social experiences, leisure time, etc., and can be incorporated into math and language curriculum.

***Short and long term auditory memory**

This is a useful area of strength to capitalize on in teaching reading. For example, preschool children can often memorize songs and story books, and begin to follow along with the text, long before they are actually able to read.

***Interest in and heightened awareness of the emotions of others**

Children with Williams syndrome are often highly sensitive to the emotions of others. For example, they may notice subtle changes in the mood of an adult, or cry tears of empathy when another child is reprimanded etc.

***Ability to initiate social interaction/conversation**

A strong motivation to interact socially can be utilized in teaching. For example, children can be paired to work on projects together, or to work as peer tutors.

***What are common areas of learning difficulty for children with Williams syndrome?***

Some tasks and learning modes can be particularly difficult for children with Williams syndrome. Following is a list of common areas of difficulty and strategies for improving them.

### 1a. Area of Difficulty

*Tasks requiring fine motor or visual-motor integration skills including:

Paper and pencil tasks, especially writing and drawing

Learning to tie shoes

Counting objects pictured on a page

### 1b. Teaching Strategies

****Computer use

Computer use should be included in the IEP, and involve teaching the use of the computer as well as using it as a tool for other materials (reading and math). This skill can eventually replace much of the paper and pencil work. It is important that the computer be used as a tool, and not simply as a reward.

*Minimize paper and pencil demands

Minimize tracing

If name writing is difficult, allow either a name stamp or writing just the first letter.

***Use real object counters to teach math, rather than objects pictured on a page

*Encourage parents to adapt clothing to maximize independence. For example:

Velcro instead of tie shoes

Velcro instead of buttons for pants if needed

### 2a. Area of Difficulty

***Tasks requiring spatial analysis including:

Learning to distinguish letters. Especially those with reversals (e.g. "b" from "d")

** Learning left and right

* Learning to tell time with a circular clock

* Orienting on a busy page such as a workbook page

### 2b. Teaching Strategies

*Simplify the amount of material presented on a worksheet (one or two problems or words per page)

This can be done easily by copying regular pages, while covering parts of the page with a sheet of paper.

*Use auditory memory skills and ability to learn from pictures in teaching reading

* Use picture cards with word labels for games such as lotto to encourage beginning sight words.

* Teach high motivation sight words before child may know all the letters

* Encourage the child to memorize picture captions and stories following the text

*A whole language approach is often successful but must be used flexibly, with stories often dictated instead of written by the child if the child has significant grapho-motor difficulty.

### 3a. Area of Difficulty

*Word finding

For some children, this is most apparent in 'stress' situations such as when they are asked a question which has only one right answer, while for many it is a problem in their spontaneous speech as well. Many children develop the strategy of 'circumlocution,' or talking around the word. This strategy, while effective when combined with a short attention span, can result in language at times seeming not to make sense. The child may begin telling about one thing, have trouble thinking of a needed word, come up with a somewhat related phrase, and move on to talking about something more related to the substitute phrase than the initial topic.

### 3b. Teaching Strategies

*Work closely with the speech therapist regarding helpful strategies to use/teach

*Phonemic cueing (providing the child with the first sound of a sought after word). This can be distracting for some children who may then just look to you and wait for the rest of the word.

*Encourage the child to gesturally cue himself (e.g. "What did you do with it - how did you use it?")

*Encourage the child to use visualization to cue himself (e.g. "What did it look like?")

### 4a. Area of Difficulty

*Learning some math skills including coins/money/time concepts, and manipulating columns of numbers (such as double digit math problems)

### 4b. Teaching Strategies

*Adapt materials

* Digital clocks and watches

* Calculator use

*Teach time concepts by personalizing

* Use wall calendars for daily, weekly and monthly schedules with events sketched or written in

* Encourage the elementary school aged child to have a date book

*Be flexible in curriculum, avoiding a rigid 'prerequisite' curriculum design

* Some children may never learn coin values but should move on to the next curriculum phase which they may be able to more readily understand

### *Should children with Williams syndrome be in regular classes?*

There is a great deal of variation in terms of classroom situations for children with Williams syndrome. The best situation for a particular child depends as much on the needs of the child as it does on the supports the school system is able to provide in regular and specialized settings. Some children will do well in regular classroom settings, while obtaining any needed therapies outside of the classroom. Curriculum adaptation and supports are strongly recommended (e.g. consultation with a behaviorist around managing attention issues or with a psychologist around friendship development; extra use of a computer for written assignments, and allowance for some breaks in work periods etc.).

Some children are in regular classrooms with an aide. With this model, it is usually most effective for the aide to spread herself across several children rather than be with the child with Williams syndrome at all times.

Children with more significant learning or behavioral issues, and/or who are in school systems with large classes and few supports often benefit from a more specialized classroom placement. This may be a classroom for children with learning disabilities, or one for children with mental retardation, depending on the educational needs of the child. We recommend that the child with Williams syndrome not be placed in 'behavioral' classrooms as their behavioral issues and needs around behavioral support are very different from those children typically placed in such classrooms.

For all children, some integrated experiences are beneficial for social - emotional development. Mainstreaming will often be more successful during somewhat more structured activities such as music, hands-on science activities or story times. Often the model of initiating mainstreaming through 'reverse mainstreaming" in which a child with interest and motivation comes to join the child with Williams syndrome in the special class for a series of visits/activities facilitated by the teacher works very well. Once the students get comfortable together, the 'buddy' can 'host' the child with Williams syndrome as he joins his friend in the regular classes.

### *Should children with Williams syndrome receive any special therapies?*

While thorough individual interdisciplinary evaluations must be done to determine the needs of a particular child, almost all children with Williams syndrome will benefit substantially from individual speech, occupational and physical therapy.

### *What should other children be told about the child with Williams syndrome?*

This varies depending on the child, family preferences and the other children. We suggest you discuss with the family what, if any, aspects of Williams syndrome the child is aware of or has discussed with the family. The teacher should ask what terms have been used so that he or she can use the same ones in any future discussion. We recommend that families have open discussions about Williams syndrome as this can be a helpful term for the child to use to explain to himself or to others why he has certain difficulties. However, some families feel it is most helpful not to use this term with the child. Whether and how a family discusses this with the child is an individual and very personal choice. There is no right way that works for all families.

Observe what, if anything, the other children notice as differences. Simple and matter-of-fact explanations in response to specific issues make the most sense to young children.

Preschool and school age children with Williams syndrome can be helped and encouraged to supply their own explanations. One school aged, highly verbal child took great pride in giving a presentation to his class each year "about my syndrome".

### *How can I learn more about children with Williams syndrome?*

The Williams Syndrome Association publishes National and Regional newsletters and maintains an

extensive library on Williams syndrome. Contact the National office in Michigan.

*Williams Syndrome Association*
*PO Box 297*
*Clawson, MI 48017-0297*
*810-541-3630*